The Missing Piece

By Aneri Pattani & Jorge Caraballo Cordovez

What is it like to live without all the pieces of the puzzle?

Executive Summary

What is it like to live without your cerebellum? What would you do if your hippocampus was removed? Our project will prompt users to explore these questions. By creating experiences that simulate brain damage or a missing brain part, our project will teach users about the role of various brain structures.

We plan to create an interactive physical experience, in which users can enter a series of rooms that correspond to different brain structures. Each room contains a challenge that utilizes the functions of that particular structure. In level 1, users complete the task with all their normal capabilities. In levels 2 and 3, a combination of physical alterations and augmented reality simulate brain damage that would make the task more difficult.

To complement the physical experience, we will create audio stories about someone who has suffered brain damage or was born without a brain structure. Users will unlock pieces of that person's story by completing each level.

User Experience

Audience

The target audience for this project is adults who do not have personal experience with brain damage.

Treatment

Upon entering the building, a staff member will greet you and give you a basic introduction *(click on the link to hear it)* to The Missing Piece in order to explain the overall premise of the project.

You then choose the first room you want to enter. You pick the cerebellum challenge.

Before you enter the room, you listen to an audio narrative *(click on the link to hear the full narrative - it would be broken into three parts in the actual experience)* about Jonathan Kelleher, a man who was born without a cerebellum. You learn that he lives alone and holds a full-time job. Yet certain tasks, like cooking and driving are still difficult for him.

Jonathan Kelleher working at the Institute for Community Inclusion at UMass Boston.

When you enter the room, you find the challenge is a driving course using bumper cars (for safety). You drive through the course with all your normal capabilities.

After completing that level, you hear the next piece of Jonathan's story, where he explains how he loves socializing with others.

When you start level 2, you are given an augmented reality headset and headphones. You navigate the driving course again, but this time, you have to dodge holographic obstacles along the way. You also encounter increased resistance in the steering wheel and pedals, which make creaking noises as you try to activate them. Once you finish the course, notifications will inform you that the obstacles simulated the difficulty people with cerebellar damage have with smooth movement. The increased resistance simulated muscle weakness.

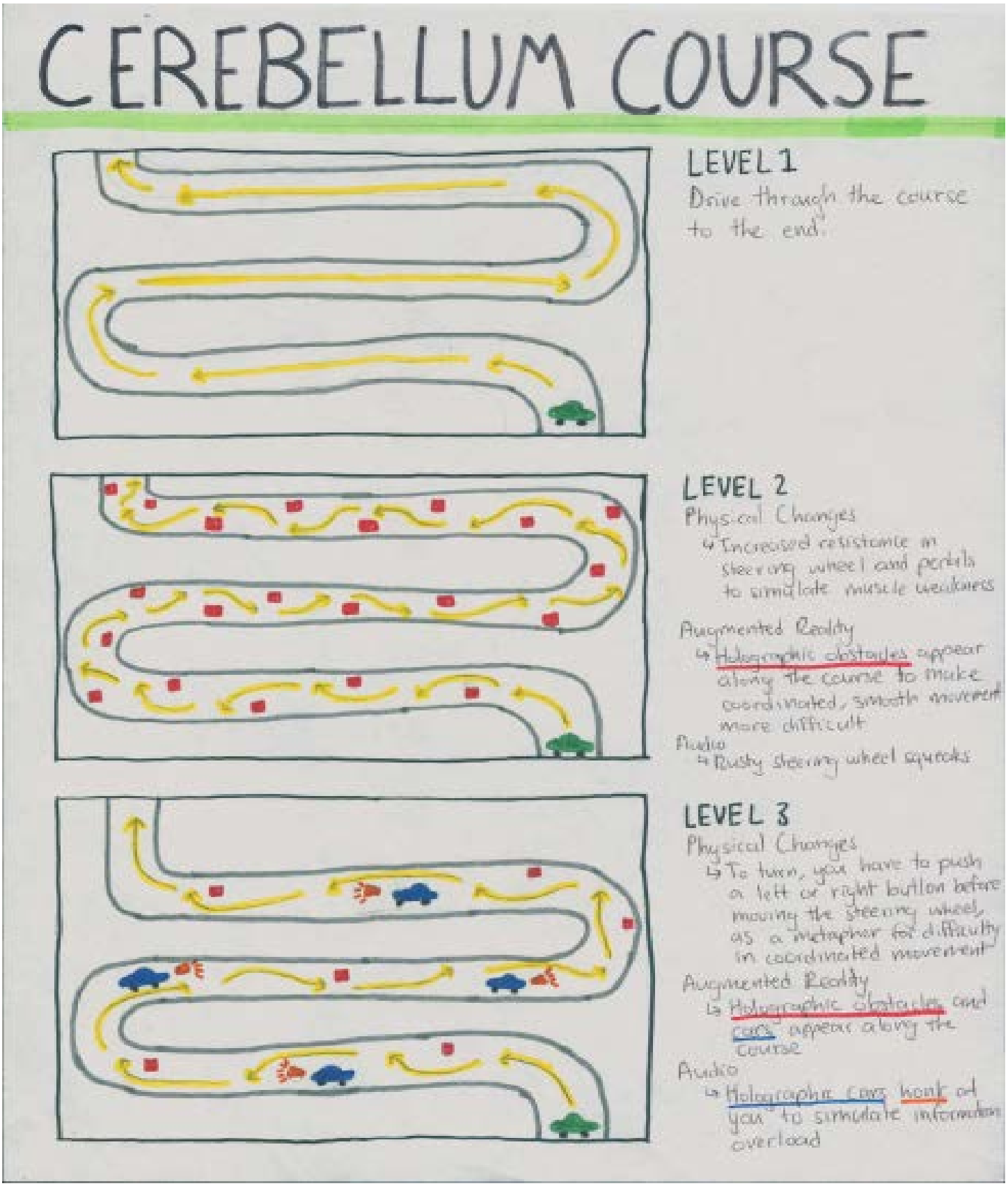
Then you hear the last piece of Jonathan's story, in which he explains that he doesn't dwell on his disability. It is simply a part of who he is.

After that, you enter level 3. The course now has other holographic cars on the road that are honking at you. There are holographic obstacles as well. Anytime you want to move the steering wheel, you have to push a button that says left or right before you can turn the wheel. Notifications will explain that this is meant to serve as a metaphor for the difficulty people with cerebellar damage have in carrying out coordinated movement.

Once you finish level 3, you're ready to move on to the next brain part.

User Experience (cont.)

Cerebellum Room: Driving Course



User Experience (cont.)

Hippocampus Room: Maze Challenge

The hippocampus challenge is a maze. In level 1, the user completes the maze without any additional obstacles. They simply have to locate the exit. They will be able to hear their footsteps echo as they walk through the room.

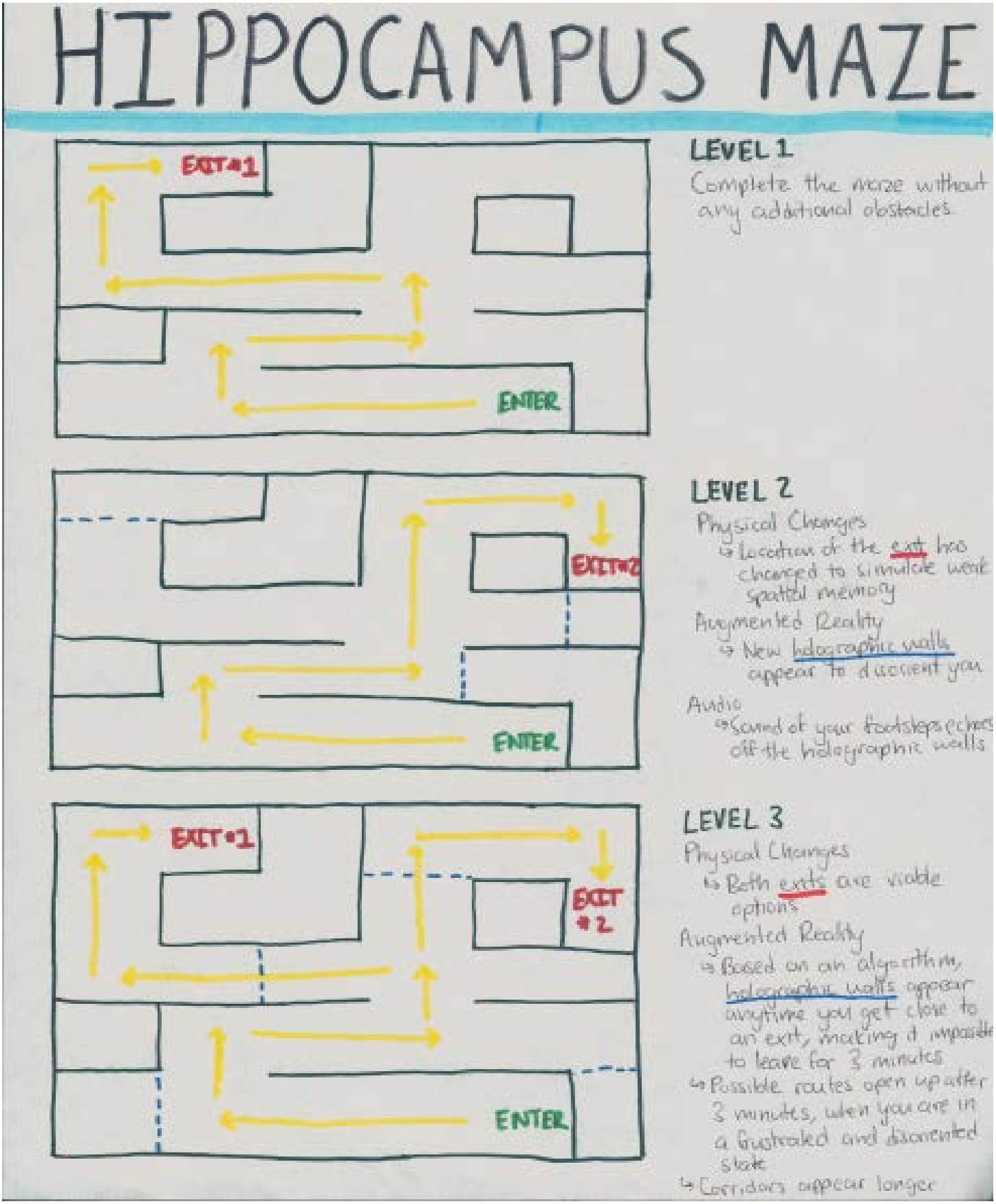
In level 2, the location of the exit is changed. This is meant to simulate a weak spatial memory that can result from hippocampal damage. The user will also encounter new holographic walls (created by HoloLens) to increase a sense of disorientation. In order to make the walls appear even more realistic, the user's footsteps will echo slightly differently as they approach the holograms. This will give the sense that the wall is solid.

In level 3, both exits are opened up as viable options. However, the user will not be able to reach either exit for at least the first three minutes. Based on an algorithm, holographic walls will appear anytime they come close to an exit. The hallways will also appear longer than before (an effect created by HoloLens). By making the challenge impossible for a short period of time,we hope to make the user understand the frustration and confusion that someone who has hippocampal damage can experience when trying to navigate relatively new spaces.

To see a demo video of a user navigating all three levels of this challenge, click here.

User Experience (cont.)

Hippocampus Room: Maze Challenge



User Experience (cont.)

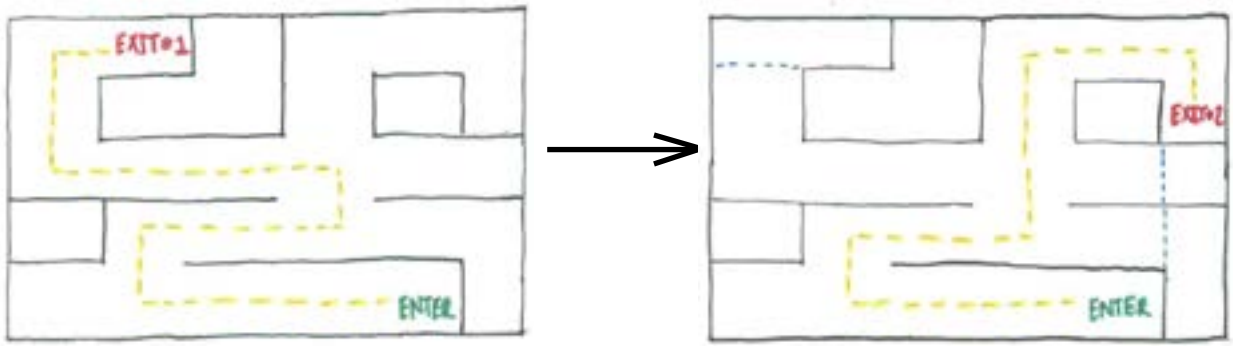
Learning

As the user progresses through each challenge, notifications will pop up in the upper righthand corner of their Microsoft HoloLens screen, alerting them to an obstacle they've encountered. These obstacles could be physical alterations, such as an item of increased weight, or augmented reality obstacles, such as the appearance of a holographic wall blocking the user's path. The user will not be able to open the notification while in the middle of the challenge. Its purpose is simply to alert them to an added layer of complexity.

Once the user completes the challenge and exits the room, they can open the notifications. Through text and visuals, the notifications will explain what type of brain damage the obstacle was meant to simulate. In this way, users not only experience diminished neural capacity, but also understand which brain structures relate to which functions.

EXIT LOCATION CHANGED

Level 1 **Level 2**



The hippocampus plays a vital role in spatial memory. People who suffer hippocampal damage often have difficulty navigating new places. To simulate this for you, the location of the exit was changed in this level of the challenge. So while you searched for the exit in the same place that it was last time, it was actually in a different corner.

A notification from the hippocampus room, in which the challenge is a maze, may look like this.

Implementation & Technical Details

Augmented Reality

Augmented reality is a new and still developing technology. It is based on the idea of adding extra layers to reality. Whiel virtual reality creates a whole new world, augmented reality uses the real world as a foundation and then builds upon that.

For example, when someone wears an augmented reality headset, they can still see the four walls around them, but they might also be able to see a bird flying around inside the room. The walls are real. The bird is not. For a video demonstration of the powers of augmented reality, click here.

We chose to use augmented reality for this project because it provides us a lot of flexibility as designers. Rather than building new sets for each level of a challenge, we can use augmented reality to impose holograms on the user's view, making them perceive the presence of obstacles that do not physically exist. This provides a safer, simpler, faster, and more cost-efficient method to add complexity to the challenges.

Several companies are currently developing augmented reality technology. Once their products are released to the market, we would be able to choose the one that best fits our need. For the sake of this theoretical design, we are using Microsoft HoloLens. It is an untethered holographic computer that enables users to interact with high-definition holograms in their world. However, this choice could change if this project were to actually be implemented in the future.

Audio

Audio cues inside each room will enhance the challenges and make the augmented reality components feel real.

For example, in the hippocampus room, the challenge is a maze. As users walk around, they hear their footsteps echo. In level 2, users will encounter holographic walls that block previously open paths. In order to enhance the experience and make the holographic walls appear realistic, the echo of users' footsteps will alter slightly, just as they would if they were to bounce off a real wall.

User Gear

Each user will be equipped with a HoloLens headset and headphones.

Implementation & Technical Details (cont.)

Physical Implementation

While actually implementing this project falls outside the scope of this class, we have thought through some broad guidelines.

For instance, we expect the the project to be created in a large warehouse-type building with at least ten rooms. The challenge inside each room would have to be custom built. As such, we don't imagine this installation changing much over time.

The project would need to keep at least ten augmented reality headsets on hand at all times. This would be enough to equip all users if each of the ten rooms was occupied at the same time.

The facility would have to be staffed. Employees would be crucial in introducing users to the experience, explaining the premise, and guiding them through the process. Employees would show users how to use the augmented reality headsets, how to access the learning notifications, and how/when to access the audio narratives.

Furthermore, the staff would need to be prepared to administer basic first aid. The project is overall very safe. We used augmented reality to ensure this. We also took certain precautions, like using a bumper car setup for the cerebellum obstacle course, because safety is a priority. However, as with most any physical experience, there is a chance of users getting injured. For instance, they could accidentally hit a wall in the maze challenge due to their disorientation. Staff need to be prepared for such instances.

With these considerations, it is clear that physically implementing this project would require a significant financial investment for the building, infrastructure, and employees.

Design Process

Options Considered

After reading the article about Patient H.M. and conducting some preliminary research, our initial project idea was to build a website that would explain the effects of surgically removing various brain structures. However, we soon found that many similar websites already existed. We also felt that this concept was not as interactive as we wanted. Thus, we started anew.

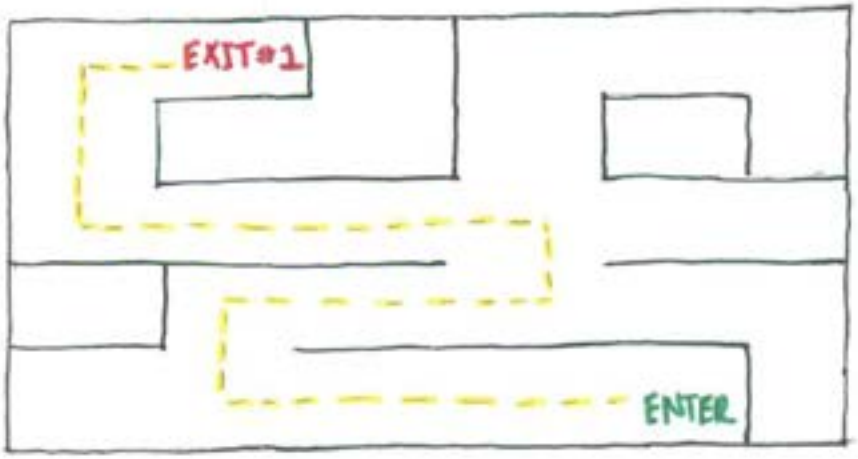
We decided to reimagine our project based on the framework of ignorance as creativity. When H.M.'s surgeon didn't know how to reduce H.M.'s seizures, he got creative and decided to remove the hippocampus. After some thought, we realized that a similar idea applied to H.M. Although he couldn't form new memories, he learned to carry on conversations in a way that someone wouldn't notice his disability immediately. His creativity was in learning to adapt to the brain damage he suffered. We decided to build on this concept: How do people adapt to brain damage? What do you approach a challenge without a certain brain structure?

From this theoretical framework, we used the concept of Boda Borg - a Swedish problem-solving game experience - to imagine a project in physical space. With Jorge's suggestion of incorporating Microsoft HoloLens, our current idea came to light.

Our initial thoughts for the two prototypes involved a maze for the hippocampus challenge and a sports course for the cerebellum challenge (shown on the next two pages). However, after receiving feedback during our mid-project critique, we decided to change the idea for the cerebellum challenge to better match Jonathan Kelleher's narrative. Jonathan, who was born without a cerebellum, talked to us about how driving is difficult for him. As such, we decided to simulate that experience by making the challenge a driving course. We hope this creates greater continuity between the audio narratives users are hearing and the physical challenges they are experiencing.

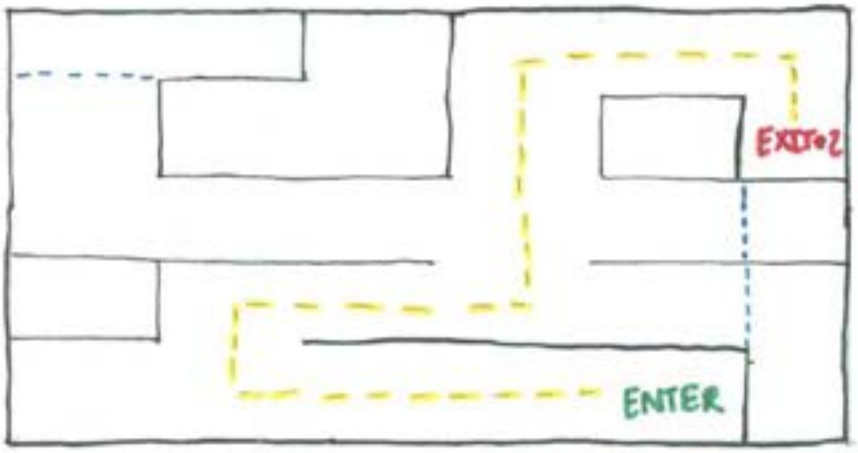
Design Process (cont.)

Initial Design for Hippocampus Room: Maze Challenge



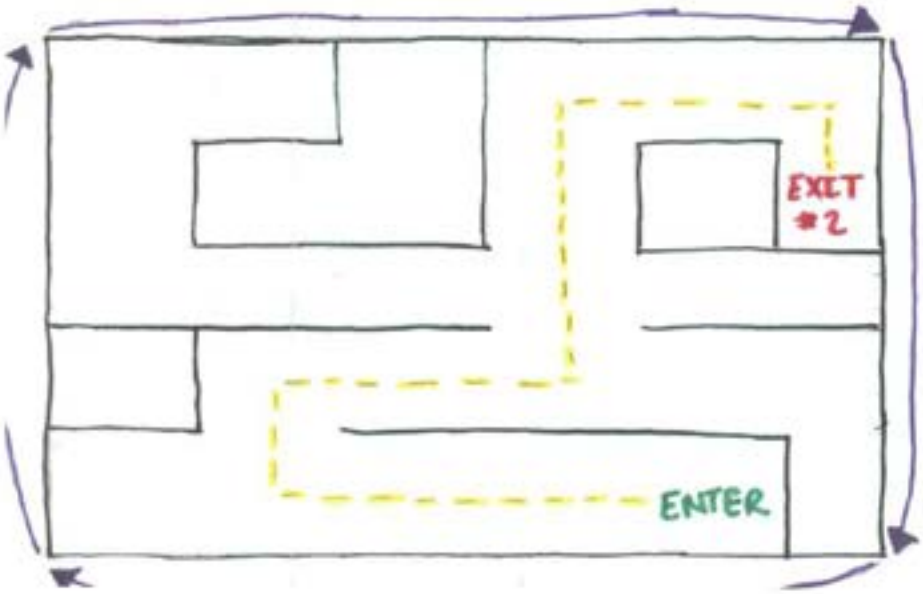
LEVEL 1

- Complete the maze without any addition obstacles



LEVEL 2

- The location of the exit has changed
  - ↳ simulates weak spatial memory
- New walls appear
  - ↳ creates a sense of disorientation

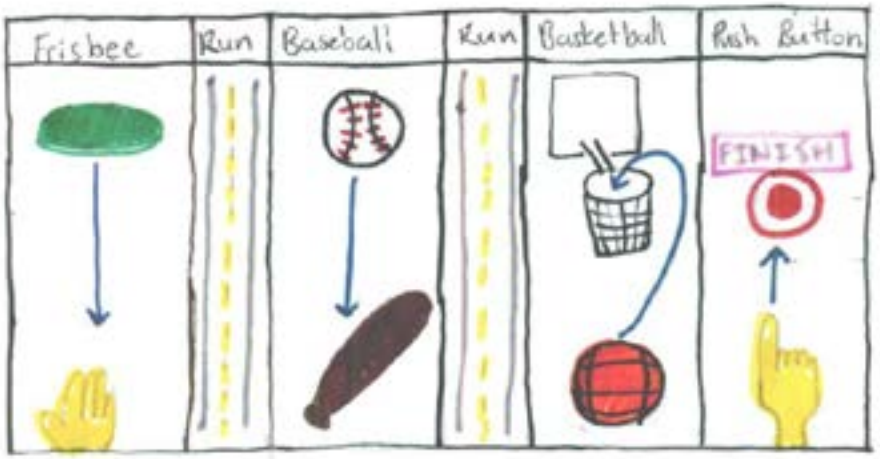


LEVEL 3

- Each straight corrido appears much longer than before
  - ↳ disrupts idea of ho long each part should take
- The entire maze appears to shift clockwise each time the person turns
  - ↳ simulates a lack of spatial mema

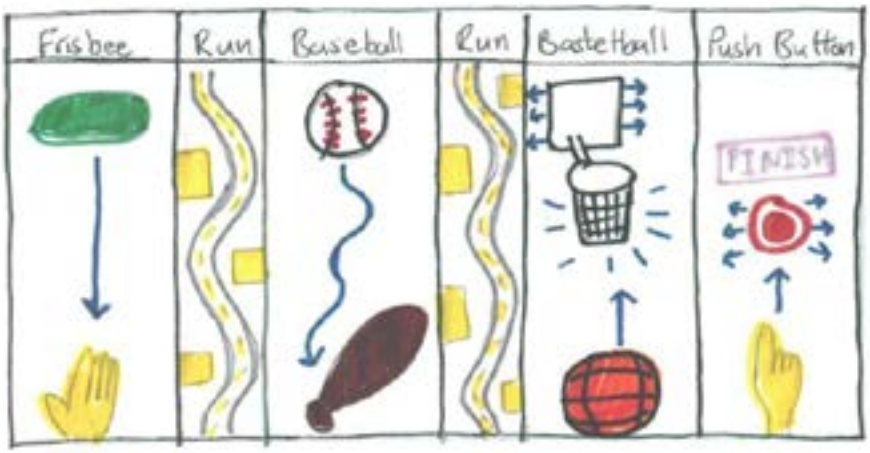
Design Process (cont.)

Initial Design for Cerebellum Room: Sports Course Challenge



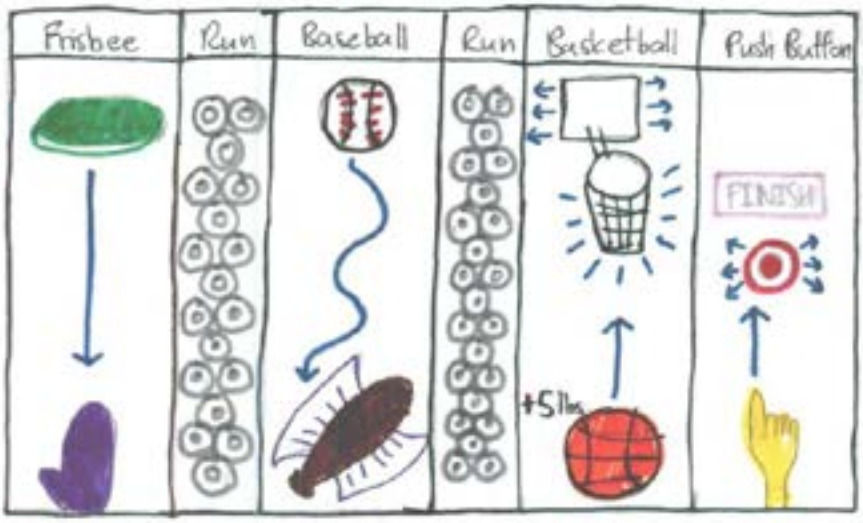
LEVEL 1

- Catch the frisbee
- Run
- Hit the baseball
- Run
- Shoot the basketball
- Press the "finish" button



LEVEL 2

- Catch the frisbee
- Run around obstacles
  ↳ simulates lack of fluid movement
- Hit baseball that seems to be swerving
  ↳ simulates poor motor coordination
- Run around obstacles
- Shoot basketball as hoop shake
  ↳ simulates poor motor coordina
- Press shaking button
  ↳ simulates poor directed moti



LEVEL 3

- Catch the frisbee while wearing mittens
  ↳ simulates lack of dexter
- Run through tire course
  ↳ simulates halted moveme
- Hit baseball using bat with increased air resistance
  ↳ simulates muscle weakne
- Run through tire course
- Shoot basketball as hoop sha with heavier ball
  ↳ simulates muscle weakne and poor motor coordinat
- Press shaking button

Design Process (cont.)

Why This Solution

We like the idea of a physical space project with challenges at several levels because it fully immerses users in the experience. They are not only reading about brain damage or hearing it, but rather, they are getting a small taste of what it could feel like. The project takes advantage of multiple senses, thus creating a more comprehensive experience than most websites can.

The format of a series of challenges also compels users to actively engage with the topic. They cannot passively consume a story. They must become a part of it. We believe this has a much greater impact and will make the stories stick more.

At the same time, this project design preserves traditional storytelling elements of narrative and explanation. While each room stands alone, users get the feeling of a continuous, sequential narrative through the fact that they're following one person's story for each brain structure. The story connects each level of the challenge, thus creating a narrative.

Additionally, through the notifications, users can learn about the subject of brain damage. This incorporates the educational aspect of journalism in what we hope will be a more fun and entertaining manner.

Team Member Roles & Responsibilities

While all major decisions are made together, each team member also has certain areas of expertise.

Aneri originated the idea for a game-room style physical installation. Jorge solved the issue of simulating brain damage by introducing the concept of augmented reality.

Aneri took on the creative process behind the design of the cerebellum room, while Jorge focused on the design of the hippocampus room. We each brainstormed possible challenges for our respective brain parts and then voted on the options together. We ultimately decided to go with a maze for the hippocampus and a driving course for the cerebellum.

Aneri found and contacted Jonathan Kelleher, but we interviewed him together. Aneri wrote and recorded the audio for Jonathan's audio narrative, while Jorge edited and produced the piece.

Jorge conducted a few additional interviews with Jonathan for a separate project. We have used some of the photos Jorge took during that time for this presentation.

Design Process (cont.)

Learning So Far

The Importance of Storytelling

When we initially conceived this idea, we only thought about the game experience. We developed challenges and thought about how to increase the difficulty at each level. We worried about the implementation of augmented reality and the notification system. But we quickly realized that we had drifted away from the heart of journalism. The thing that makes an article, a video, a book, or any other journalistic product compelling is not its technical finesse, but the story behind it. Thus, we decided to refocus our project on stories.

We developed the concept of the audio narratives and began searching for characters. When we found Jonathan Kelleher, it was clear that we had found an amazing story. It breathed life into our entire project. The challenges only accomplish the purpose of teaching users about brain damage if users can also hear from people who live with such challenges day in and day out.

Connecting the Dots

Since our ideas about the challenges and the audio narratives developed separately, we initially treated them as two separate projects. We continued developing challenges for the hippocampus and cerebellum based on our research, and then conducted interviews with Jonathan Kelleher separately.

After receiving feedback at the mid-project presentation, we realized this was a flawed approach. By failing to connect our challenges to the audio narratives, we were creating a disjointed experience. Users would have a much easier time understanding what it's like to live with brain damage or a missing brain part if they were confronting the same types of challenges that they were hearing about in the audio narratives.

This realization led us to revise our challenge for the cerebellum room. Instead of a sports course, we decided to use a driving course, as that accompanied Jonathan's story.

We did not adjust the hippocampus challenge, as we have not found a character for that audio narrative. However, if we were to continue developing this project, we would likely adjust the challenge to remain consistent with the human story that accompanies it.

Safety First

Journalists typically do not need to consider the physical safety of their audience. It is unlikely that someone will injure themselves while reading a newspaper or watching a network broadcast. However, when journalism is taken off the pages and into a physical space, safety suddenly becomes very important.

Even though we are not actually creating this project, we tried to keep the safety of users in mind throughout our design. One of the main reasons we chose to use augmented reality is because this technology allows us to create obstacles in a safer manner.

Design Process (cont.)

Learning So Far (cont.)

Sensitivity and Accuracy

One of the most important things we have learned so far is that the subject matter of brain damage must be handled with great sensitivity. For instance, we decided not to record the amount of time users took to complete each challenge because we realized that might convey a sense of competition. This would trivialize the difficulties of living with brain damage and miss the mark of our project.

Furthermore, it was pointed out to us by people at the UMass Boston Institute for Community Inclusion that we should be careful to explain that completing a few tasks cannot replicate the challenges of living with brain damage day after day. Thus, we included a statement to this effect in the staff member intro.

Additionally, in designing the tasks, we have learned that we must speak to people living with brain damage in order to create an accurate experience. We plan to keep this in mind during our iterative process.

The second time we spoke with experts from ICI (pictured below), they were pleased to learn about this measure, saying it is important not to generalize brain damage, since each person experiences the consequences differently. They also were pleased to hear we had shaped the cerebellum challenge around the specifics Jonathan had shared with us about his experience driving. As such, we feel we are on the right path to create a thoughtful and accurate project.

ICI Experts Maria Paiewonsky (left) and Nancy Hurley (right)

Next Steps

Theoretical

If we were to continue this project, there would be three main steps that we would need to take.

First, we would have to find someone who is living without a hippocampus or who has suffered hippocampal damage to help us develop the audio narrative for the hippocampus room. We might find this person by reaching out to neuroscientists who study brain damage or organizations that help people with disabilities related to neural damage. Based on their narrative, we might end up changing the hippocampus challenge, as we did for the cerebellum room after we met Jonathan Kelleher.

Secondly, we would want to conduct some basic user testing to get feedback on our idea. We would interview people unfamiliar with the project to see if it would be interesting for them and if it would fulfill our objective of teaching them about brain damage. We could discuss our project idea with various members of the Northeastern and Boston community in order to get such general user feedback. Is this an exciting prospect? Would they want to try it? Do they think it would be educational? The answers to such questions would help us make the most engaging experience possible.

Finally, after revising our plans based on the user feedback, we would need to go ahead and develop ideas for challenges related to other brain parts. In order to justify the use of a physical space and the time people would have to dedicate to such a storytelling experience, we think the users should be given a choice of 10 brain parts. Thus, we would need to repeat the process of research, conceptulization, and design in order to create challenges for eight other brain parts.

We recognizine that building an interactive storytelling experience requires constant revision and refinement, and that is what we would have to plan to do in order to bring this project to fruition.

In Practice

While we most likely will not bring this project idea to fruition due to various factors - money, time, lack of organizational support - we do hope to bring part of our work to life. As journalists, we are fascinated by people's stories and want to share them with the world.

In this case, we found Jonathan Kelleher's story of living without a cerebellum inspiring and amazing. We have already created an audio narrative around his story, but we also hope to create a video about a day in his life.

These products, while certainly less comprehensive than our project idea, will still work toward the same goal of helping people understand what it is like to live with a missing piece.